

# Addressing Fertility in Patients With Advanced Cancer: How the Quality Oncology Practice Initiative Standards and ASCO Guidelines Facilitate Ethical Communication

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## Vignette

The patient is a 35-year-old married man with one child who presented with abdominal discomfort, rectal bleeding, and normal performance status. A colonoscopy detected an obstructing adenocarcinoma of the colon. Staging demonstrated bilobar liver metastases and scattered low-volume lung metastases. He underwent a right hemicolectomy and was then referred to a medical oncologist. The oncologist reviews the standard toxicity profiles of the agents she expects to use in treatment of this patient, including fluorouracil, oxaliplatin, irinotecan, bevacizumab, cetuximab, and panitumumab, and then prepares to meet with the patient and his wife. The oncologist's practice participates in ASCO's Quality Oncology Practice Initiative (QOPI); she is aware of the QOPI measures, which assess discussion of infertility risk and potential fertility preservation options or referral to a fertility specialist in accordance with ASCO guidelines. The oncologist believes that this patient's disease is incurable and feels conflicted about the appropriateness of discussing fertility with the patient and his wife.

## Background of ASCO Guidelines on Fertility Preservation

The 2006 ASCO Recommendations on Fertility Preservation in Cancer Patients<sup>1</sup> provide guidance for oncologists on fertility preservation methods and related issues in patients being treated for cancer. The guidelines specifically recommend that oncologists address infertility risk in patients of reproductive age at the earliest possible opportunity as part of the pretreatment informed consent process, regardless of prognosis. The guidelines also recommend that oncologists be prepared to discuss fertility preservation options and/or refer appropriate patients and their families to reproductive specialists.

ASCO subsequently added two practice quality measures on fertility preservation to the QOPI program in 2007 to reflect these recommendations.<sup>2</sup> Though the ASCO guidelines do not clearly define "appropriate" patients (other than specifying those of reproductive age), the QOPI program established age-based parameters to provide guidance on choosing appropriate patients for fertility discussions. Subsequent discussions within the QOPI program have ensued regarding disease stage, disease prognosis, and curability. However, the current specifications do not yet exclude patients from the measures on the basis of these factors.

Despite these published recommendations,<sup>1</sup> evidence suggests that a significant proportion of oncologists are unaware of

ASCO's fertility guidelines, and many are reluctant to initiate conversations pertaining to fertility with patients. A recent national survey by Quinn et al<sup>3</sup> of oncologists found that fewer than 25% of oncologists reported routinely referring patients for fertility preservation, and only 38% reported knowledge of the ASCO guidelines. Data from the QOPI program also reveal that many oncologists are not discussing the infertility risk involved in chemotherapy and fertility preservation options in their practices. There are a number of obstacles to addressing fertility with patients, but a key obstacle is the concern among oncologists that discussing the risk of infertility and fertility preservation is neither appropriate nor an immediate clinical priority in patients with advanced or poor-prognosis disease.<sup>3-5</sup>

## Discussion

**Is infertility a concern for patients with incurable malignancies?** Several studies have confirmed that fertility is important to patients with cancer, both at time of diagnosis and after completion of cancer treatment.<sup>6,7</sup> Many patients with cancer are concerned about their ability to have children in the future, and in some cases, this concern may influence their decisions about cancer treatment.<sup>6</sup> Although fertility concerns are common among patients with cancer and have a significant impact on quality of life and survivorship, to our knowledge, there are no studies specifically seeking to understand the attitudes of patients with incurable cancers or address communication about risk of infertility and fertility preservation in patients whose cancers are incurable.

**Why does offering fertility preservation to a patient with incurable cancer seem troublesome or inappropriate for many oncologists?** A practicing oncologist is faced with many emotionally charged issues when disclosing to a patient that he or she has advanced cancer. Expectations at an initial visit include skillful communication of diagnosis, therapeutic options, and clinical trial availability; review of therapy-related toxicities; and discussion of prognosis. Each one of these issues requires thoughtful and sensitive communication. With such patients, a discussion of issues surrounding infertility risk and fertility preservation is equally challenging, and to some oncologists, it may seem inappropriate.<sup>8</sup>

The oncologist in this vignette may feel conflicted about raising fertility issues with her patient for several reasons. First, the oncologist may feel that raising the issue of having children in the future would be insensitive in light of the patient's poor prognosis, and she may be concerned that any discussion of

fertility would send mixed messages about what the patient should expect for his future. Although it is more of an issue with female patients, the oncologist may also be concerned that a patient's choice to pursue fertility preservation could delay chemotherapy, possibly compromising treatment outcomes and impeding the delivery of quality care. The oncologist's own views about whether it is appropriate for the patient and his wife to consider having another child at this time may also be a factor. The oncologist may be concerned about long-term adverse effects on a child who seems destined to lose a parent to cancer. On the other hand, the oncologist must weigh the possible negative psychosocial effect that losing the possibility of having more children may have for the patient and his wife during an already difficult time. There are numerous reasons why the oncologist may feel conflicted and uncomfortable in this situation, but not talking to the patient about fertility preservation is essentially the equivalent of making a choice for the patient and his wife. Even if having additional children may not be possible for a patient with incurable cancer, it is important for the patient to make the choice to pursue or forego fertility preservation independently on the basis of information provided by the oncologist.

**What do the ASCO guidelines recommend when addressing infertility risk and fertility preservation in the incurable patient?** On the basis of the ASCO guidelines,<sup>1</sup> one of the QOPI measures assesses whether oncologists discuss infertility risk with their patients before they begin anticancer therapy. The guidelines do not suggest that oncologists exhaustively review or recommend fertility preservation options. By offering the opportunity to explore the issue, oncologists are acknowledging that concerns about fertility are common among patients with cancer and that the issue is worth discussing. By offering patients an opportunity to discuss specific questions about infertility and fertility preservation and offering referrals to a specialist, oncologists satisfy the spirit of the QOPI measure and respect the ethical tension they often experience in this difficult situation.

Because discussing infertility risk and fertility preservation with patients not being treated with curative intent may be uncomfortable, the topic should be handled carefully and sensitively. For example, one way to introduce the topic is as follows:

“We have discussed that chemotherapy and/or other treatments may slow the growth of your cancer, but your cancer is not curable. However, many patients in your situation still wonder about having children. I realize that the news of your cancer prognosis is very upsetting, but if you would like to discuss the issue of having children in more detail, I would be happy to go over that with you and/or refer you to a specialist if you would like to consult with one.”

## Conclusion

Concerns about future fertility are common among patients with cancer and have a significant impact on quality of life. Despite a lack of empiric data, it is likely that issues surrounding fertility are also concerning for patients with incurable cancer. The ASCO guidelines<sup>1</sup> appropriately encourage practicing oncologists to address these concerns formally with patients and their families. The QOPI measures assess whether discussions and referrals take place when appropriate and are a useful mechanism for practice self-assessment and quality improvement efforts. Although there are significant barriers to communication about fertility regarding all patients with cancer, patients being treated with curative intent need to be informed about infertility risk before initiation of therapy, and fertility preservation options ought to be explained in detail. For patients not being treated with curative intent, the ASCO recommendations<sup>1</sup> and QOPI measures still reinforce the notion that oncologists ought to provide an opportunity to discuss risk of infertility and address concerns about fertility preservation.

Although initiating conversations about fertility with patients with incurable disease may be difficult, and the issue may engender strong feelings related to morality for oncologists, decisions about reproduction are extraordinarily personal and need to be left up to patients and their families. The role of the oncologist is not to serve as a gatekeeper of information for the patient just because the patient might make a decision the oncologist believes would be inappropriate. Rather, the oncologist ought to assess the needs and concerns of the patient with advanced disease through discussion and facilitate access to information as needed. By recognizing how important issues of fertility and reproduction are to most patients with cancer of reproductive age, the ASCO guidelines<sup>1</sup> and QOPI quality assessment measures regarding communication about infertility and fertility preservation are appropriate—though challenging—additions to the overall effort to improve the quality of cancer care.

*Accepted for publication on August 31, 2009.*

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## Acknowledgment

*We thank Karen Hagerty, Pamela Mangu, Kristen McNiff, and Pam Kadlubek for their contributions to this article.*

## Authors' Disclosures of Potential Conflicts of Interest

*The authors indicated no potential conflicts of interest.*

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DOI: 10.1200/JOP.091038; posted online ahead of print at <http://jop.ascopubs.org>

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